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AUTHOR Brunk, Gary L.
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ABSTRACT

This study identifies the factors that have contributed most to supporting growth of self-advocacy among people with developmental disabilities, by examining the history of self-advocacy and reporting on interviews with six self-advocates and six advisors of the self-advocacy movement. The study concludes that the growth of self-advocacy has been greatly assisted by the power of example, that the movement has emphasized learning by doing, that self-advocacy groups provide a supportive and safe environment where persons who have been undervalued are able to gain a new sense of confidence and possibilities, that self-advocacy requires material support and ideological support, and that self-advocacy is important enough that it is worth being supported by persons and institutions outside the self-advocacy movement. Specific recommendations are made for ways in which agencies and professionals who work with persons with developmental disabilities can support the further growth of self-advocacy. (32 references) (JDD)

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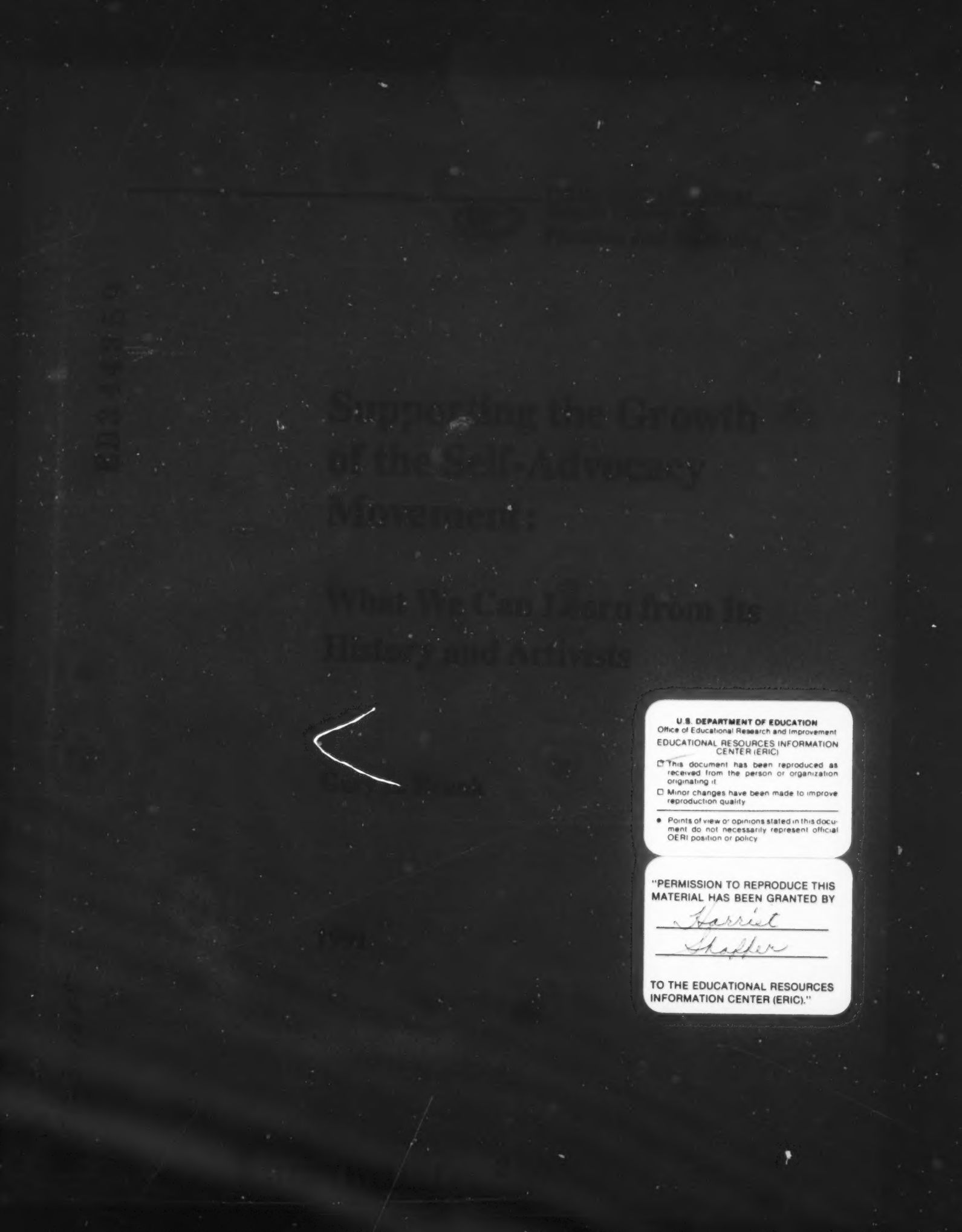
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Supporting the Growth of the Self-Advocacy Movement:

What We Can Learn from Its History and Activists

PO-11

Gary L. Brunk

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DRAFT

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Abstract

The self-advocacy movement in North America among people with developmental disabilities has grown rapidly since its beginnings in the mid-1970s. This study identifies the factors that contribute most to supporting growth of self-advocacy by examining the history of self-advocacy and reporting on interviews with leaders and veteran advisors of the self-advocacy movement. It then makes specific recommendations for how agencies and professionals who work with persons with developmental disabilities can support the further growth of self-advocacy.

Supporting the Growth of the Self-Advocacy Movement:

What We Can Learn from Its History and Activists

In 1974 the first self-advocacy conference in the United States was organized by persons with developmental disabilities in the state of Oregon. Since then hundreds of local self-advocacy groups have formed across the United States and Canada and around the world, helping justify the frequent use of self-advocacy movement in descriptions of this development (People First of Washington, 1985; Rhoades, Browning, & Thorin, 1986).

Many self-advocacy groups exist in relative isolation from each other, but in several states there are now either well developed networks of groups or formal statewide organizations with elected officers and paid staff. Furthermore, national self-advocacy organizations have recently formed in Canada and the United States. While it may still be accurate to describe the self-advocacy movement as fragile, it is clear that it is more than just a passing phenomenon (Brunk, 1987).

The purpose of this study is to understand why self-advocacy has grown as rapidly as it has in order to identify the factors that contribute most to supporting its growth. The study first examines the history of the development of self-advocacy in the United States. This section is based primarily on written sources, including speeches and articles by persons with developmental disabilities who have been involved in the self-advocacy movement.

The second section is based on interviews with leaders of the movement and nondisabled self-advocacy advisors. The interviews were used to draw information from the persons who are currently most directly involved in the self-advocacy movement. The third section summarizes the information from the first two sections and draws some conclusions.

Understanding the Growth of Self-Advocacy

The North American self-advocacy movement seems to have its roots in the social clubs for people with mental disabilities that existed in Sweden in the 1960s (Williams & Shoultz, 1984). Those social clubs emphasized the importance of decisionmaking by their members and supported that emphasis by providing training in parliamentary procedures and real experience in decisionmaking through the election of officers and participation in committees (Nirje, 1972).

As those clubs developed they began exchanging visits and organizing regional meetings. Those interactions culminated in a national conference in Malmo attended by 48 representatives from throughout Sweden and two guests from Denmark. The purpose of the May 1970 conference in Malmo was to discuss concerns related to leisure activities, residential living, and employment, but the real significance of the conference was that it was perhaps the first organized articulation of a desire for greater self-determination at a national level by persons with mental retardation (Nirje, 1972; Williams & Shoultz, 1984).

That desire found expression throughout the conference, as evidenced by the following excerpts from a summary of the findings of the conference:

> We all agree that we want more rights to participate in decisions, especially in planning and carrying out our leisure time activities.
>
> We all think one should decide oneself what to do during vacation. There should be student councils [in Sweden's special schools] which can take part in decisions about the curriculum, the choice of books, leisure time in school, etc.
>
> We want to choose our vocations ourselves, and have influence over our education.
>
> We think we should be present when our situation is discussed by doctors, teachers, welfare workers, foreman, etc. (Nirje, 1972)

The Malmo conference inspired conferences in Britain in 1972 and in British Columbia in 1973. Five persons from Oregon attended the conference in British Columbia. Three were residents of the Fairview Hospital and Training Center, a state institution, and the other two were staff members from Fairview. The Oregon group returned enthused about the idea of a statewide conference and organization and were able to convince other persons, both inside and outside of Fairview, of the value of organizing a conference. Their efforts led to a conference in

1974 that attracted 560 people and a second conference in 1975 that was attended by 750 people. Persons with mental disabilities were involved in all aspects of planning, organizing, and leading both conferences. While nonhandicapped persons did provide support and advice, they did so in ways that would encourage the development of skills and leaders among the persons with disabilities (Edwards, 1982; Williams & Shoultz, 1984).

Oregon continued having annual conferences, but perhaps more importantly, it became a model and source of inspiration for the formation of other self-advocacy groups across the country who contacted them or who saw a film about the second conference called *People First* (Edwards, 1982; Rhoades, et al., 1986; Williams & Shoultz, 1984). In addition to the groups that had been inspired by Oregon, there were also self-advocacy groups that began forming independent of the events in that state, as well as some that had pre-dated the Malmo conference (Williams & Shoultz, 1984).

Several hundred self-advocacy groups involving several thousand persons with mental disabilities have formed in the U.S. and Canada since the first two Oregon conferences. One study in the early 1980s identified 152 groups and estimated that those groups had a total of 5,000 members (Browning, Thorin, & Rhoades, 1984). We can make a more current estimate based on a recent directory of self-advocacy groups which lists 380 groups (Association for Retarded Citizens, 1990). If we use the same

formula used by the Browning study, the estimated number of members would exceed 12,500. These numbers underestimate the real growth of self-advocacy because the ARC directory does not include groups the author has contact with in New York, Kentucky, and Kansas, and there may be other groups that are not included.

In the last decade one of the significant developments has been the growth of viable statewide self-advocacy organizations. People First of Washington was one of the early statewide organizations with the funding needed to maintain staff, offices, and communications essential to a functioning organization. Since 1981 it has opened three offices, hired a staff (over 50% are persons with developmental disabilities), and grown to 46 groups (Association for Retarded Citizens, 1990; People First of Washington, 1985 & 1986; Rhoades, et al., 1986).

Statewide organizations have formed in other areas. In New Jersey, the United Self-Advocates held their sixth annual conference in June 1990. The conference was attended by 450 people representing over 50 groups (New Jersey Self Advocate, 1990). Almost 300 people from five groups attended the Speaking for Ourselves conference in Pennsylvania in May 1990 (Speaking for Ourselves, 1990). And in New York, a new statewide organization drew 250 persons to its first self-advocacy conference in the summer of 1990 (Self-Advocacy Association of New York, undated).

More recently, self-advocates in the United States have taken steps to form a national organization. At a conference in Estes

Park, Colorado, in September 1990, 400 self-advocates voted to form a national organization and elected a steering committee to make recommendations about the mission and structure of the organization (National Steering Committee of Self Advocates, 1991). Then at a second national conference in Nashville, Tennessee, in September 1991, 700 self-advocates ratified a proposal to form a national coalition of state and local self-advocacy groups, coordinated by a Steering Committee composed of elected regional representatives (B. Carabello, personal communication, September 9, 1991).

Likewise in Canada representatives from regional organizations met in Winnipeg in March 1990 to debate a draft constitution that will lead to the formation of National People First (Laroche, 1990).

What explains the extraordinary growth in self-advocacy among people with mental retardation? I suggest that the clue to understanding this growth lies in the conflict between, on the one hand, an existing social construction of disability that relegated people with mental retardation to an inferior and segregated status and, on the other hand, a new ideology and practice of equality and integration. That conflict became particularly acute in the mid-1970s, creating in the process both motivation and a new space that encouraged the growth of self-advocacy. In what follows I will seek to elucidate my argument.

The Social Construction of Disability

The experience of disability is the result of a time and culturally specific social construct; the key elements of that social construct will vary according to the disability (Bogdan & Taylor, 1982; Gliedman & Roth, 1980; Minow, 1990; Sarason & Doris, 1979; Scheer & Groce, 1988). If we want to understand the lives of persons with disabilities we need to understand the nature of the specific construct of disability that is relevant to them.

An illuminating example of a specific social construct of disability can be found in Groce's (1985) study of persons who were deaf living in Martha's Vineyard. From the time it was first settled by Europeans in the 17th century until the early 20th century, Martha's Vineyard has had a high percentage of persons with hereditary deafness. Groce found that in their education, marital status, employment opportunities, economic standing, civic participation, and social interactions, persons who were deaf on the Vineyard did not differ from persons who were not deaf. This was a striking contrast to the situation of persons who were deaf on the mainland during that same period, who were marginalized and segregated.

Groce identifies two factors that explain the integration of persons who were deaf on the Vineyard. One was that the prevalence of deafness contributed to an attitude of acceptance because people thought that it could happen to anyone. The second factor was that virtually everybody on the island used sign

language, thereby eliminating the most important barrier between persons who were and were not deaf.

The attitudes of acceptance and the lack of communication barriers were the key elements of the social construction of deafness on the Vineyard and explain why the situation was so different from the situation of persons who were deaf who lived on the mainland. That difference is forcefully highlighted in a remark made to Groce by a woman she interviewed in the course of her research, who told her, "Those people weren't handicapped. They were just deaf" (p. 5).

The Retarding Environment

In 1983 the California State Council on Developmental Disabilities contacted People First of California to conduct a needs assessment among persons with developmental disabilities. The task force that conducted the assessment consisted of six persons who were members of the Capitol People First self-advocacy group, two advisors, and a writer.

After interviewing over 150 clients and service providers in a variety of settings, the task force concluded that

> many people are better off for *not* getting services from institutionalizing and devaluing parts of the system. We also saw clear evidence that people who do get genuine *developmental* services do better than people who get traditional services. When all factors are the same, including the type and degree of biological impairment, the

> evidence seems very strong that the ones who become able to lead the most normal lives are those who have been helped to the greatest extent *outside* of the traditional service system. In short, the task force suggests a new phrase to be used to sum up the nature and effect of . . . the traditional system of services for the mentally retarded . . .: THE RETARDING ENVIRONMENT.
>
> The retarding environment is found in state hospitals, in sheltered workshops, in segregated educational facilities, and often in integrated special education programs. It is found, tragically, in almost every type of program, and even more tragically, in the attitudes of so many of the *keepers* of the system. (People First of California, 1984, p. 10; emphasis in original)

In effect, what the People First task force describes in its report are some of the aspects of the social construction of mental retardation in the United States.

One important element of the retarding environment that the People First task force highlighted is the persistence of attitudes that devalue people with mental retardation, a reverse parallel to Groce's identification of accepting attitudes as one of the keys to understanding the situation of persons who were deaf on Martha's Vineyard.

Persons with mental retardation themselves are acutely aware of this devaluation, which they often experience as *invisibility*.

Stephen Dorsey, a leader in the self-advocacy movement in Pennsylvania, says:

> Most people look at us, *but they don't see us.* I have been in a workshop . . . for 17 years. Last month, I gave a speech to the Delaware County Association for Retarded Citizens. . . . I read some of the speech I gave in Washington on the Medicare Reform Act. After I had finished, a staff member [from my workshop] came up to me and said, 'I'm impressed, Stephen, very impressed. *I didn't even know you could read.*' That's what I mean by 'looking at us, but not seeing us.' (InterServe, undated, emphasis in original)

In a similar vein, a leader of the self-advocacy movement in Nebraska, Nancy Ward, relates this story:

> I used to work in a sheltered workshop. . . . My boss became ill. She had to quit. Before she did, she talked to me about applying for her job. I didn't have any confidence in myself. After talking to other people about it, I finally decided it wouldn't hurt to at least fill out an application. When I tried to fill out the application, the personnel department would not even let me fill it out. This made me upset, but I went back to work. A couple of weeks later, several staff members came to the workshop building with the new supervisor. After talking with them, I was told to train the new supervisor. Therefore, I quit

and found another job. (Ward, 1989, p. 14)

These stories reflect the recurrent experience of having one's abilities ignored or underestimated, not on the basis of an objective evaluation of a person's real skills, but as the result of preconceived notions that are the result of prevailing attitudes toward people with mental retardation.

There are two noteworthy aspects of these stories. The first is that both Stephen Dorsey and Nancy Ward have rejected the validity of those devaluing attitudes. In doing so they undermine the current social construct because its continued existence depends on the passive consent of persons with mental retardation who have accepted and internalized those attitudes.

The second aspect is that they are describing experiences *within* the system of social services for people with mental retardation. As People First of California makes clear in their description of the retarding environment, a key element of the social construction of mental retardation is a service system which encourages dependency instead of independence. This is not surprising since those services are the result of a broader public policy that has in general not supported the self-determination of people with disabilities.

Berkowitz (1987), in his analysis of disability policy in the United States, notes that the funding for programs that seek to integrate people with disabilities into the economic and civic life of their communities is a small fraction of the funding for

programs that simply transfer money to persons assumed to be incapable of being productive and contributing citizens.

This observation holds true if we look more specifically at public policy in the area of mental retardation. In his examination of how federal funds are used for mental retardation programs, one of Braddock's (1987) conclusions was that there was a continuing institutional bias. In FY 1985, $1.918 billion, or almost 25% of all federal funds for mental retardation and developmental disability (MR/DD) programs, went toward the maintenance of 100,000 persons in public institutions. In contrast, funds for special education and rehabilitation grants amounted to 4.8% of MR/DD expenditures. Since 38.5% of federal MR/DD funds go to income maintenance programs, that means that almost 2/3 (38.5 + 25 = 63.5%) of federal spending supports keeping people in institutions and/or out of the workplace.

What I have sketched above are some of the pieces of the social construction of mental retardation. They include the existence of widespread negative attitudes that devalue and dehumanize persons with mental retardation and that are accepted and internalized by the devalued persons. Those attitudes are reinforced by a system of services that segregate persons with mental retardation and at the same time encourage their dependence. In turn, those services are guided by a public policy that has in general not supported self-determination.

The social construct of mental retardation that relegates

people with mental retardation to an inferior and segregated status was in place in the early 1970s when the self-advocacy movement began and is still largely in place today. To understand how, in spite of this social construct, the self-advocacy movement was born and continues to flourish, we need to examine briefly the growth of a countervailing set of forces and ideologies that created a space for self-advocacy.

Opening a Space for Self-Advocacy

In October 1961 President John F. Kennedy appointed the President's Panel on Mental Retardation. What perhaps differentiated this panel from previous efforts to recommend and institute broad changes in the area of mental retardation was President Kennedy's own interest in implementing reforms because of his personal connection to the issue through a sister with mental retardation. Within a year of the Panel's report, Congress passed legislation that incorporated many of its recommendations, including funds for maternal and infant care, research centers, teacher training, and demonstration projects. A significant aspect of the legislation was the emphasis on the provision of community-based services (Scheerenberger, 1987; Tyor & Bell, 1984).

President Kennedy's commitment helped focus renewed attention at the federal level on policy issues related to mental retardation, a trend that continued into the 1970s. This attention was encouraged by advocacy organization and particularly

by the National Association for Retarded Children, which had been founded by parents in 1950 and experienced rapid growth throughout the 1950s (Tyor & Bell, 1984).

The social movements of the 1960s, especially the civil rights movement, also had a significant impact on developments in the MR/DD field. This impact took various paths, one of which was through the court system. The most important example of how civil rights decisions in the courts shaped disability issues was the 1954 Supreme Court decision in *Brown v. Board of Education*. The principles enunciated in *Brown* were an important basis for court decisions in the early 1970s that established the right to free, appropriate public education for children with disabilities and that culminated in the Congressional enactment of the Education for All Handicapped Children Act (P.L. 94-142) in 1975 (Turnbull, 1990).

A similar impact was felt in the legislative arena, where the key piece of civil rights legislation directly affecting people with disabilities--Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112)--was patterned after the Civil Rights Act of 1964 (Scotch, 1984).

But perhaps of most importance to the development of self-advocacy was the impact of the civil rights movement on professionals and on people with disabilities. As a result of the civil rights movement, many professionals began to understand retardation as a social problem, one particularly tied to the

persistence of poverty in America (Tyor & Bell, 1984). At the same time, the civil rights movement was helping some people with mental retardation gain a new perspective on themselves (Worth, 1989).

These developments gave impetus to a search among professionals for a reconceptualization of the goals of their work, and perhaps no single concept in the field of mental retardation had as much impact as the concept of normalization. Not coincidentally, the concept of normalization was born in Scandinavian countries during the period that saw the development of the Swedish social clubs noted above. It was first articulated in the United States at a conference in 1969 by the Director of the Danish Service for the Mentally Retarded and the Secretary General of the Swedish Parents Association (Scheerenberger, 1987).

In the U.S. and Canada the most influential proponent of normalization was Wolf Wolfensberger, who in an early definition of the concept wrote that normalization was the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (1972, p. 28).

While the concept was not without controversy, normalization seemed to go a long way toward responding to the desire for fresh ways of thinking about issues related to mental retardation and "became the professional ideology of the 70s" (Tyor & Bell, 1984, p. 148). Three related ideas that helped fill the conceptual void

became widely accepted by professionals in that period: (a) the belief that people with mental retardation were capable of growth and development (the developmental model), (b) the legal notion of least restrictive environment, and (c) the importance of integrating children with disabilities in regular classes, or mainstreaming (Sarason & Doris, 1979; Scheerenberger, 1987; Turnbull, 1990).

These concepts found a practical expression in the growing demand among some professionals in the late 1960s and early 1970s for the deinstitutionalization of people with mental retardation, a demand that was reinforced by the occasional media exposes of truly horrifying conditions in some institutions (Rothman & Rothman, 1984; Scheerenberger, 1987; Tyor & Bell, 1984).

I briefly described above a social construct of mental retardation--the retarding environment--which, as the result of the prevalence of negative attitudes and of the nature of the programs and policies that are supposed to serve the needs of persons with mental retardation, constantly reinforces passivity and dependence. It is in the fissures of this construct that the new ideology of normalization, equality, and integration began growing in the late 1960s and early 1970s.

This ideology created the space that was needed for people with mental retardation to assert themselves as citizens, but the ideology had been articulated largely by persons who were professionals and/or advocates. If persons with mental

retardation were to actually begin rejecting oppressive attitudes and institutions, they needed to be supported in those efforts. Self-advocacy groups provided that support by creating an environment where peers could learn from each other about their rights and responsibilities and where they could practice the leadership, problem-solving, and social skills that were essential to the exercise of their rights.

Washington People First, one of the early statewide self-advocacy organizations, explains self-advocacy in this way:

> When we say that People First is a 'self-advocacy' organization, we mean that the members are:
> - 'speaking up and speaking out' for themselves
> - solving their own problems and making their own decisions
> - knowing and exercising the full rights and responsibilities of citizenship
> - contributing to and participating in the community (1986, p. 2)

This succinct explanation reflects what persons with disabilities say when they talk about what self-advocacy means to them:

> Speaking up and speaking out is self-advocacy. Making your own decisions, being more independent. Standing on your own two feet and sticking up for our rights is self-advocacy. . . .
>
> In self-advocacy you can learn from each other, you can

> teach each other so much. In Nebraska, we have a course to teach self-advocates how to teach other self-advocates. It focuses on how to vote, civil and legal rights, and what self-advocacy is. . . . Self-advocacy is important because it makes people feel independent and as a result experience personal growth. (1985, pp. 8-9)

Self-advocacy groups support individual change and development, but self-advocacy has in turn been supported by sympathetic professionals and advocates. That support is most visible in the role of the advisor or helper, usually a person without a mental disability who assists the group while being very careful to not take control of its decisionmaking processes. While it has been argued that some self-advocacy groups may reach a point where an advisor is not needed, in practice the role of the advisor has been essential to the maintenance of many self-advocacy groups (Browning, et al., 1984; Curtis, 1984). In addition to the support provided by individual advisors, the institutional support of established advocacy organizations and government agencies has also been important. Thus, the states that witnessed the fastest growth in self-advocacy groups--New Jersey and Washington--have been the ones where financial support from other organizations was available for a central office, communications, and technical assistance.

Self-advocacy will need further support from individuals and institutions if it is to continue growing, and in the next part of

this paper I explore what self-advocates and their advisors think are optimal forms of support.

The Perspective of Self-Advocates and Advisors

The first section of this paper has examined the history of the development of self-advocacy in the United States to help identify the factors that have contributed to its growth. In this section I want to draw directly from those most involved in the growth of self-advocacy, the veteran leaders and advisors of the self-advocacy movement.

I conducted phone interviews with six self-advocates and six advisors in different parts of the country. The self-advocates were all persons with developmental disabilities who are leaders in their local and state organizations and are recognized by other self-advocates as spokespersons for their groups. The advisors were all persons with long-standing involvement in self-advocacy who had experience with local groups and with state or regional self-advocacy organizations. The interviews were tape recorded and the recordings were then summarized and analyzed. One recording with an advisor was not audible, thus reducing the number of advisors used in the subsequent summary to five.

Question 1: When you reflect on the growth of self-advocacy in your state, what do you think has contributed most to supporting its growth?

The role of self-advocates. The most salient point of agreement on this question was that it was self-advocates

themselves--through face to face interactions and the power of their testimony--who were most responsible for the growth of self-advocacy. Of the 11 persons interviewed, five self-advocates and three advisors emphasized the essential role self-advocates play in promoting the growth of self-advocacy.

Self-advocates said that it was important to have persons with disabilities speak to others with disabilities about self-advocacy and to share their stories and experiences. One self-advocate spoke about the need to have regular meetings and conferences where people could learn from each other.

Advisors were even more emphatic about the role self-advocates had played in promoting self-advocacy. One veteran advisor to a seven-year-old statewide project, which has helped get over 50 groups started, said that she thought that experienced self-advocates had been essential to getting those groups started. She described the function of the project as that of going around the state giving permission and information: "This is what people are doing and you can do this if you want to." But she emphasized that the success was due in large part to the fact that it was self-advocates who were giving the permission.

Another advisor also noted that permission had much more power and impact when it came from self-advocates. He spoke of how, in his experience, self-advocates were more effective than professionals in helping change low self-expectations of other persons with disabilities to high self-expectations and in helping

them understand that they are allowed to want things from life.

Outside support. A second area of agreement that was mentioned by three self-advocates and four advisors was the importance of having persons outside the self-advocacy movement who understood and supported self-advocacy. One advisor talked about how in his state there had been a history of citizen activists and of key people in the service delivery system who believed in persons with developmental disabilities making their own choices and who were prepared to make resources available to support self-advocacy when it began to develop.

Advisors also spoke about the importance of specific types of outside support: (a) financial support for statewide projects for staff salaries and for holding specific events such as conferences, (b) in-kind support for copying, transportation, office space and phones, and (c) a monthly column in a parent organizations newsletter.

Self-advocates and advisors emphasized the value of educating parents and professionals about self-advocacy and about the rights and the potential of people with disabilities as a way to increase support for the self-advocacy movement. One self advocate said that having good advisors was important.

Question 2: If you were the director of a local or state program working with people with disabilities, how would you use your organization's resources to support the growth of self-advocacy?

Greater involvement in decisionmaking. Two self-advocates

and two advisors said that as directors of an agency they would involve persons with disabilities in the decisionmaking process. All of them agreed that persons with disabilities should be represented on the boards of directors of agencies, and three suggested specific measures to help assure that the representation was more than token.

One advisor said that persons with disabilities should make up half of the board and that they should be paired in a buddy system with the nondisabled members who could help them understand the issues and provide them with whatever support was needed to maximize their understanding and participation.

One self-advocate had been on a statewide board and had been assisted by a translator who attended the meetings, went over agendas and minutes with him, explained the issues that were coming up, and drew pictures to communicate concepts that were otherwise difficult. He said that having a translator was very helpful and that all boards should do it. An advisor also advocated using translators and further suggested that meetings should be structured in ways that allow greater participation. As an example, he described a statewide board where people with developmental disabilities can call a break at any time they feel a need to get together to figure out what is going on.

In addition, one advisor said that he would encourage people with disabilities to become involved in decisions about the hiring, evaluating, and firing of agency staff.

Staff and board training. One self-advocate and three advisors said that as directors they would provide training about the value and philosophy of self-advocacy for their staff and board members.

The self-advocate said that he would talk to the staff about how important self-advocacy was. One advisor said that staff and boards needed to understand that day-to-day encouragement for people with disabilities to do things and make decisions for themselves was the most effective way to empower people. Another advisor said that staff needed to have a firm grounding in normalization. All three advisors agreed that persons with disabilities should have a significant role in the training; one of them said she would have persons with disabilities run her training program.

Financial support. Three self-advocates and one advisor said that as directors they would provide financial support to self-advocacy groups.

Two of the self-advocates were adamant that the financial support should only be partial so that the groups would also be involved in other forms of raising money. One of them said that he would give them half of the money they needed and would monitor how it was spent. The other self-advocate said that groups needed to raise their own money because fundraising should be a joint responsibility. The concern of the advisor was that agency's financial support should have no strings attached to it so that

decisions of the groups would remain free.

Independent living. One self-advocate and two advisors said that as directors they would use their agency resources to help people with disabilities live independently in the community.

The self-advocate said that he would help people get out of institutions so they could live in the community. One advisor said that he would provide support for people to buy their own homes and to start their own businesses. He also said that it was important to pay attention to the social needs of people as they begin living in the community by helping set up friendship circles or other forms of support.

Transportation. One self-advocate and two advisors said that as directors they would help arrange for transportation to meetings of self-advocacy groups.

Conclusions

In this section I want to draw some conclusions about what factors contribute to the growth of self-advocacy, based on the review of the history of the self-advocacy movement and the interviews with self-advocates and advisors, and suggest how agencies and professionals providing services to adults with developmental disabilities could use those conclusions.

The Power of Example

One important conclusion is that the growth of self-advocacy has been greatly assisted by the power of example.

There are two kinds of exemplary activity. One is what

groups do that inspires and instructs others, who then want to replicate what they observed. An important illustration of this in the history of the self-advocacy movement was the visit of five persons from Oregon to a conference in British Columbia, which gave them a vision of what people with developmental disabilities could themselves do, who then returned to Oregon to organize a statewide conference that drew 560 persons and a second one the following year that was attended by 750 persons. Those conferences, through a film of the second conference and as the result of people learning about them and contacting the Oregon self-advocates, are often credited with inspiring the formation of groups across the country.

The second kind is the power of exemplary individuals who, in relating their stories and in speaking about what self-advocacy has meant to them, open up new worlds of previously unimagined possibilities for other persons with disabilities. As noted in the interviews, those leaders help liberate others, giving them permission to speak for themselves and helping create new expectations for themselves and their lives.

Agencies and professionals could: (a) provide assistance for persons with disabilities to attend self-advocacy conferences and training sessions, (b) bring in self-advocacy leaders to speak to the persons they serve, (c) hire experienced self-advocates for their staff.

Learning by Doing

From the beginning, the self-advocacy movement has emphasized learning by doing. The members of the Swedish social clubs learned how to make decisions about their club activities by receiving training in parliamentary procedures and then practicing what they had been taught through elections and participation in committees. That practice has remained an essential activity of most self-advocacy groups, which have focused a lot of their time and energy on teaching and practicing decisionmaking, problem-solving, and social skills as part of their ongoing activities. A discussion and vote on how a group can raise money, for example, is important for the possible outcomes, but it is equally as important for the experience gained in how to present ideas, convince others, make decisions, assign responsibilities, and carry them out.

The persons interviewed who said that as directors of agencies they would involve persons with disabilities in the decisionmaking processes of their agencies and would provide support for living independently were in effect extending the practice of learning by doing beyond the relatively safe context of the self-advocacy group. Participation on boards of directors, especially when measures are taken to ensure meaningful participation--such as creation of a buddy system; provision of translators; involvement in decisions about hiring, evaluating, and firing staff; or living independently in the community--are

practical ways to teach choice and decisionmaking skills.

Agencies and professionals could: (a) have a significant number of persons with disabilities on boards of directors, providing them with the support needed to ensure they are not just token participants; (b) have persons with disabilities on personnel committees; (c) train staff on methods for encouraging persons with disabilities to make choices day by day.

The Importance of the Group

Self-advocacy groups provide a supportive and safe environment where persons who have been undervalued are able to gain a new sense of confidence and possibilities.

Earlier it was noted that self-advocates such as Steve Dorsey and Nancy Ward have rejected the notion that as persons with developmental disabilities they could be routinely ignored. That act of rejection is often extremely difficult, because it is done in the face of a pervasive social construction of disability that affirms the relegation of persons with disability to the margins of society. For many persons with developmental disabilities that rejection would not be possible without the support of their self-advocacy group. That is reflected in the emphasis self-advocates give to learning from each other and teaching each other when they talk about the meaning of self-advocacy.

Agencies and professionals could: (a) assist persons with disabilities to find and participate in an appropriate self-advocacy group; (b) sponsor a self-advocacy group by helping find

an advisor and providing other forms of support.

The Value of Material Support

Self-advocates and advisors interviewed for this study underscored the importance of material support for self-advocacy from groups and individuals outside the self-advocacy movement. The kinds of support mentioned included financial support and in-kind support for transportation, office space, phones and copying.

Agencies and professionals could: make available resources such as copying, transportation, and use of phones to a self-advocacy group.

The Importance of Ideological Support

In the historical review we examined how a constellation of related concepts that included normalization, the developmental model, the least restrictive environment, and mainstreaming formed the core of a new ideology that emerged in the 1970s. That ideology was adopted by some professionals and parents and helped create space within the retarding environment for the growth of self-advocacy. That ideological support remains important for several reasons. First, it helps ensure the availability of sympathetic persons who are willing to be advisors to self-advocacy groups. Second, it helps parents think about their children with developmental disabilities with enhanced expectations for independence, thus making their efforts to speak for themselves easier. Third, it increases the likelihood of material support from outside the self-advocacy movement.

Because material and ideological support are so important, the continued education of staff and parents is likewise important. The persons interviewed suggested training in normalization, the value of self-advocacy, and the importance of day-to-day encouragement of persons with disabilities to make decisions. They also suggested that self-advocates have a significant role in the training.

Agencies and professionals could: (a) use self-advocates to help train staff and board members; (b) assist self-advocates in organizing and making presentations to parent, professional, religious, government, and civic groups in the community.

Support by Those Outside Self-Advocacy

Finally, we should ask if self-advocacy is important enough that it is worth being supported by persons and institutions that are outside the self-advocacy movement. While there are many possible affirmative answers, I want to answer that question in light of the recently enacted Americans with Disabilities Act (ADA) of 1990 (P.L. 101-336).

The ADA adopts a minority model, stating in its findings that persons with disabilities are a "discrete and insular minority" who have been "relegated to a position of political powerlessness." The Act goes on to say that

> the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-

sufficiency.

In order to fulfill those goals the Act extends civil rights protections to persons with disabilities, which are designed to guarantee equality of opportunity in employment, public accommodations, transportation, state and local government services, and telecommunications. While the ADA might immensely broaden opportunities, those opportunities cannot become realities for persons with disabilities unless they are prepared to act on them, that is, unless they can shed passivity and dependence and become self-determining citizens. The law establishes the new horizon of opportunities, but only individuals acting on the basis of their own choices and preferences are in a position to make those opportunities come true.

Because the self-advocacy movement provides the supportive environment that many persons with mental retardation need in order to embrace and practice self-determination, it seems important to in turn provide the movement with the support it needs to maximize its impact.

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Beach Center on Families and Disability

The University of Kansas
% Institute for Life Span Studies
3111 Haworth Hall
Lawrence, Kansas 66045

Co-Directors: Ann P. Turnbull
and H. Rutherford Turnbull, III

(913) 864-7600
(913) 864-5323 FAX